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ABSTRACT

Parents/correspondents (N=500) of residents at a large public residential facility for the retarded were surveyed concerning their attitudes toward the community placement of their family member. One-half of the surveys originated from and were returned to the public facility, the other half of the surveys originated from and were returned to the Developmental Disabilities Planning Council (D.D.P.C.) to control for respondent bias. The survey return rate was 64%. Of those returned, 74% indicated that the public facility was the most appropriate placement at the present time and 67% indicated that the public facility would be the most appropriate placement in the future. A majority of the parents/correspondents (79%) indicated that they were satisfied with the programming and care provided by the public facility and only 14% agreed with a court order to reduce the population in the state facilities. (Author/CL)

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ATTITUDES TOWARDS DEINSTITUTIONALIZATION HELD BY FAMILY MEMBERS OF INSTITUTIONALIZED MENTALLY RETARDED PERSONS*

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Abstract

Parents/correspondents of residents at a large public residential facility for the retarded were surveyed concerning their attitudes toward the community placement of their family member. One-half of the surveys originated from and were returned to the public facility, the other half of the surveys originated from and were returned to the Developmental Disabilities Planning Council (D.D.P.C.) to control for respondent bias. The survey return rate was 64%. Of those returned, 74% indicated that the public facility was the most appropriate placement at the present time and 67% indicated that the public facility would be the most appropriate placement in the future. A majority of the parents/correspondents (79%) indicated that they were satisfied with the programming and care provided by the public facility and only 14% agreed with a court order to reduce the population in the state facilities.

ATTITUDES TOWARDS DEINSTITUTIONALIZATION HELD BY FAMILY MEMBERS OF INSTITUTIONALIZED MENTALLY RETARDED PERSONS

The purpose of this study was to determine the attitudes of families of institutionalized mentally retarded people toward community placement and compare these results to the findings of Meyer (1980). The study surveyed 500 families of residents at Cambridge State Hospital (CSH) in East Central Minnesota. The survey form was adapted from a questionnaire developed by Meyer (1980) who surveyed families of residents at Western Center in Canonsburg, Pennsylvania. The results of Meyer's study suggested that the majority of the families of institutionalized mentally retarded residents do not wish to have their family members placed in the community although they did agree with the idea of placement for other residents. In fact, Meyer found that 83% of the parents stated that the institution was the most appropriate placement and 79% were satisfied with the programming and care provided at Western Center.

In light of a recent court decision in Minnesota (Welsch v. Noot, 1980) which requires a 30% decrease of the institutionalized mentally retarded population within seven years, it was important to determine if similar concerns existed in the CSH catchment area. This includes nine counties in East Central Minnesota; 76% of the residents are from the metropolitan area of Minneapolis and St. Paul and the remaining 24% from rural areas.

Method

Meyer's questions (Meyer, 1980) were modified to relate to CSH and some additional questions were added. The questionnaire consisted of

fifteen items. The first seven obtained demographic data (e.g., county of residence, length of stay). Two questions asked the correspondent to define two attributes or behaviors of their family member that would be either assets or hindrances to community placement. A brief description of group homes, supervised apartments and foster care facilities was then given, and the correspondents were asked to indicate which setting they felt their family member would best be served both today and in the future. A question was then asked concerning the correspondent's attitude toward the recent Minnesota court order (Welsch v. Noot, 1980). Two questions were then asked concerning what changes were necessary to accomplish community placement for their family member. The final question concerned the correspondent's satisfaction with the programming and care provided at CSH. The majority of the questions were multiple choice while several included a request to give specific reasons for the choices that were made.

Meyer used surveys that were completed anonymously by the correspondents in order to obtain more honest answers to the questions concerning attitudes towards community placement. Our concern was that even though the survey was completed anonymously, respondent bias (i.e., telling the hospital what the respondent thinks the hospital wants to hear) could still be a factor. Surveys were therefore randomly assigned and mailed from either CSH or the State of Minnesota Developmental Disabilities Planning Council (DDPC) in order to control for respondent bias.

The surveys were mailed to all available correspondents of residents at CSH (N = 500) and consisted of a cover letter explaining the survey and the questionnaire. A current mailing address was not available for a few of the correspondents. The surveys for the two groups were identical but the return addresses and cover memo letterheads were either from CSH or

the DDPC. The correspondent was asked to return the survey anonymously within two weeks. To increase the return rate all correspondents were sent a follow-up postcard reminding them to return the survey as soon as possible if they had not already done so. These postcards were sent from the same source as the original survey.

In addition to determing the attitudes of the parents/correspondents concerning deinstitutionalization and comparing these findings to Meyer's study the possibility of respondent bias was evaluated. In evaluating each of these points it was important to verify that the returned surveys were a representative sample of the actual population at CSH. This was verified by comparing the demographic data from the returned surveys with the demographic data from the actual hospital population.

Results

The survey return rate was 64% or 322 out of 500. Of these returns, 49% were completed by mothers, 13% by fathers, 30% by both the mother and the father, 4% by a sister or brother and the remaining 4% by others.

One of the demographic questions asked the correspondent to indicate the sex of their particular family member. The tally of this question shows that 60% of the returns represent male residents, 39% of the returns represent female residents, and that 1% of the respondents left this item blank. This was consistent with the actual population at CSH that was 57% male and 43% female.

The age of the resident, based on the returned surveys, had a range from three years to 65 years of age with a mean age of 29.4 years. This was also consistent with the CSH population which has a range from three years to 65 years of age and a mean age of 29.8 years. The returns indicated that the residents have been at CSH from one to 51 years and had

an average length of stay of 16.8 years. The hospital records reflected an average length of stay of 17.1 years and a range of several months to 57 years.

A question concerning the mobility of the correspondent's family member was asked. The following results paralleled the demographic data compiled by the hospital concerning the total population:

51% - walk independently

4% - walk with supportive device

14% - walk unaided with difficulty

1% - wheelchair - operated by self

15% - wheelchair - needs help

12% - no mobility

3% - blank

One of the questions dealt with the correspondent's attitude toward the placement of choice for their family member at the present time. That is, where did they think their family member would best be served? The majority of the respondents indicated that CSH was their placement of choice for today. Cambridge State Hospital was the choice indicated by 66% of the respondents, 8% gave multiple responses where CSH was one of the options, and 17% indicated that a group home was their placement of choice. The remaining 9% of the responses were spread across several groups. (See Table 1)

Insert Table 1 About Here

A similar question was asked concerning the correspondent's placement of choice in the future. Again, the majority of the responses to this question indicated that CSH was the placement of choice for their family

member. Cambridge State Hospital was selected by 61% of the respondents, 6% gave multiple responses that included CSH, 16% indicated a group home as their placement of choice, and 12 % did not answer this question. (See Table 1)

Correspondents were asked their opinion concerning a recent federal court order requiring deinstitutionalization. Fourteen percent of the respondents indicated that they were in agreement with the court order, while 39% did not agree. Thirty-seven percent indicated they were uncertain about the court order, and 10% did not respond to this question.

As with Meyer's survey a question was asked to determine how the correspondents view the service and care provided by the public facility. The responses indicated that 79% of the respondents were satisfied with the services and care, 5% were not, 5% were uncertain and 11% did not answer this question.

The surveys were randomly assigned to originate from either CSH or the DDPC in order to control for respondent bias. The random assignment was supported by the comparison of the demographic data between the two groups. The responses from these two groups were then compared on four particular items:

1) TODAY - Choice of placement for today.
2) FUTURE - Choice of placement for the future.
3) SATISFACTION - Satisfaction with programming and care at Cambridge State Hospital.
4) COURT ORDER - Agreement or disagreement with the court order.

The pattern of responses to each of these questions was very similar, therefore, respondent bias did not influence the responses. For example, Cambridge State Hospital was the preferred current placement by 65.2% of the surveys that originated from CSH and 66.5% of the surveys that

originated from the DDPC. Concerning the court order, 13.9% of the CSH group was in agreement with the court order and 14.0% of the DDPC group was in agreement.

In addition to the tabulation of the responses to individual questions, several comparisons were made between two variables. For example, it appears from the responses that the older the respondent the more likely that CSH was the current placement of choice. (It should be noted that this may also be confounded with the fact that an older respondent most likely has a family member that is older, and that this family member may represent an individual who has been in the institution for a longer period of time.) Figure 1 demonstrates the trend to choose Cambridge State Hospital as the placement of choice as the age of the respondent increases.

Insert Figure 1 About Here

The data from this survey is similar to the data obtained by Meyer (1980) in Pennsylvania not only in the attitude of the respondents but also in the demographic data. For example, the percent of returns for male residents was 57% in Meyer's study and 60% in the CSH study with a smaller number of returns for females (42% and 39% respectively). These accurately reflect the actual populations of the institutions. In both studies it was the mother who most often completed the survey (51% v. 49%) with a much smaller number of fathers responding (18% and 13%). The mean age of the residents was almost identical (29.3 years v. 29.4 years). The age of the respondents was also similar with the largest group between 51-65 years (50% and 43%) and the next largest group being 36-50 years old (31% and 25%). Table two provides complete information for these comparisons.

Insert Table 2 About Here

The attitudes in both surveys were similar with the majority of the respondents selecting the institution as the placement of choice not only for today but also for the future. In both surveys the majority of respondents indicated that they were satisfied with the programming and care that is being provided by the hospital (78.7% and 79.1%, Meyer and CSH respectively). Each of the surveys included a question concerning recent court decisions that required deinstitutionalization. In both surveys a small percentage of the correspondents (8% and 14%) were in agreement with the court decision, a larger number did not agree (66% and 39%), and a significant number were uncertain about how they felt concerning the court ruling or left this item blank (26% and 47%). Table three provides complete information for these comparisons.

Insert Table 3 About Here

Although the majority of the questions required the respondent to circle a multiple choice answer, written responses were requested for several of the questions. For these questions, specific reasons were requested for the choices made. Two of these questions included preferences and reasons for placement now and in the future.

The reasons given for choice of placement now were analyzed and fell into ten groups. Of the 336 reasons given by the 306 respondents 36.6% gave the perceived level of functioning of their family member as the reason for making their choice. Of these 109 chose the state hospital, 8 chose multiple options which included the state hospital, and 6 listed the

resident's perceived level of functioning as the justification for placement in a group home.

The next most frequent reason given was the quality of care with 22.3% of the total responses. Of these, 47 chose the state hospital, 2 chose options which included the state hospital, 23 chose a group home, and 3 chose foster care.

Miscellaneous answers were given by 30 of the respondents and 30 gave resident satisfaction as the reason for their choice. Of those mentioning resident satisfaction, 21 chose the state hospital, 1 gave a multiple option including the state hospital, 7 chose a group home, and 1 chose foster care. Categories for written responses concerning current placement are shown in Table 4.

Insert Table 4 About Here

For future placement 294 respondents gave 318 reasons for their choices. The residents perceived level of functioning accounted for 28.9% of these responses. Of these, 83 were for future placement in a state hospital, 3 for multiple options including the state hospital and 6 for a group home.

Responses based on the quality of care represented another 20.0% of the responses for placement in the future. Of these 42 chose the state hospital, 1 multiple options including the state hospital, 18 chose a group home, 3 chose foster care, and 12 gave no reason for their choice.

The residents perceived satisfaction was the basis for 6.9% of the reasons for future placement. Of those listing resident satisfaction, 17 chose the state hospital, 1 chose multiple options which included the state hospital, 3 chose a group home and 1 chose a supervised apartment.

Four percent preferred that their relative remain in the state hospital because they had been there for years. Four percent based their choice on a home-like environment with 11 of these choosing a group home and 2 choosing foster care. The closeness for purposes of visiting was the basis for 3.5% of the responses. Of these, 6 chose multiple options including the state hospital, 4 chose the state hospital and 1 chose a group home. The state hospital was the placement of choice for 1.3% of the responses because community placement had failed in the past. Another 1.3% stated that they had no knowledge of alternatives. Of these 2 chose the state hospital and ? chose multiple options including the state hospital. Reasons for future placement are categorized in Table 5.

Insert Table 5 About Here

Discussion

The results from this particular study appear to support the findings of Meyer (1980). While comparison of the demographic data suggest that both institutions serve similar populations, differences may exist in the functioning level of the residents, length of institutionalization, and other unknown areas. In both cases, however, the majority of respondents preferred placement at the institution both now and in the future. The majority of both groups expressed satisfaction with the quality of programming and care at their respective institutions, and only a small percentage expressed agreement with a court decision requiring community placement.

The factor of respondent bias was originally perceived as a possible weakness with Meyer's study. However, the data did not support this but rather indicated that respondent bias was not a factor in this study and

most likely is not a factor in Meyer's study.

Some reasons given for deinstitutionalization such as a home-like environment or geographic closeness to family were not the most important concerns of the respondents. While very few respondents expressed concern over their lack of knowledge regarding alternatives to institutionalization the written responses clearly indicated that many respondents lacked correct information and that much needs to be done in this area if future choices are to be made based upon accurate information. This apparent lack of information may impact on deinstitutionalization in several ways. First, by reducing the support needed for additional funding of programs for the developmentally disabled. Second, by complicating team decisions concerning appropriate placement. Third, by influencing family support for team decisions. Overcoming this problem will require the cooperation of many agencies including state hospitals, group homes, county family services and advocacy groups. These groups need to create a system to provide accurate information to family members of mentally retarded persons on the services available both within the institution and within the community.

Table 1

Percent of Respondents Choosing Each Placement

Placement	Today	Future
Cambridge State Hospital	65.8%	60.9%
Group Home	17.1%	15.6%
Multiple Response w/CSH	8.4%	6.2%
Multiple Response w/o CSH	2.2%	2.8%
Foster Care	.9%	1.2%
Supervised Living	.3%	.6%
Other	.6%	.6%
Blank	4.7%	12.1%

Table 2

Relationship of Respondent to the Child/Ward
for Returned Surveys

Respondent	Meyer's Study	CSH Study
Mother	51%	49%
Father	18%	13%
Mother and Father	7%	30%
Sister and Brother	15%	4%
Aunt or Uncle	3%	1%
Other	6%	3%

Age of Respondent Completing the Survey

Age	Meyer's Study	CSH Study
20-35 years	3%	3%
36-50 years	31%	25%
51-65 years	50%	43%
66 plus years	15%	25%
Blank	1%	4%

Table 3

Comparison of Meyer's Results With The CSH Results

Item	Meyer	CSH
Satisfied with Programming/Care	78.7%	79.1%
Placement of Choice - Today		
Remain at Hospital	83.1%	*65.8%
. . .		+8.4%
Group Home	13.5%	17.1%
Other	1.1%	4.0%
Blank	2.2%	4.7%
Placement of Choice - Future		
Remain at Hospital	76.6%	*60.9%
. . .		+6.2%
Group Home	15.7%	15.5%
Other	3.3%	5.2%
Blank	4.4%	12.1%
Agreement with Court Order		
Agree	7.7%	14.0%
Disagree	65.9%	38.8%
Uncertain	19.4%	37.3%
Blank	6.9%	9.9%

* The additional percentage comes from those respondents that selected multiple placements which included CSH.

Table 4

Reasons Given By Respondents For Current Placement Of Choice By Type of Placement

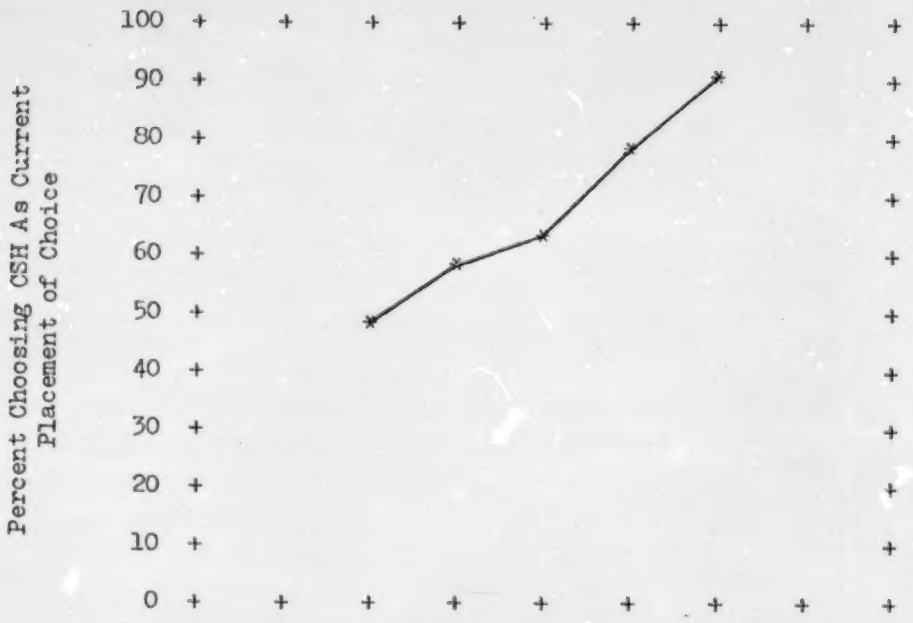
	Group Home	Supervised Apartment	Foster Care	Remain at CSH	Mult. Option w/CSH	Total
Quality of Care	23	0	3	47	2	75
Level of Resident	6	0	0	109	8	123
Community Placement Failure	0	0	0	4	0	4
Close to Visit	1	0	0	4	1	6
Resident Satisfaction	7	0	1	21	1	30
No Knowledge of Alternatives	0	0	0	0	1	1
Home-like Environment	8	0	2	1	0	11
Has Been in Hospital for Years	0	0	0	8	0	8
Miscellaneous	7	0	1	13	8	30
Blank	9	0	1	37	1	48
Total	61	0	8	224	22	336

Table 5

Reasons Given By Respondents For Future Placement
Of Choice By Type Of Placement

	Group Home	Supervised Apartment	Foster Care	Remain at CSH	Mult. Option w/CSH	Total
Quality of Care	18	0	3	42	1	64
Level of Resident	6	0	0	83	3	92
Community Placement Failure	0	0	0	4	0	4
Close to Visit	1	0	0	4	6	11
Resident Satisfaction	3	1	0	17	1	22
No Knowledge of Alternatives	0	0	0	2	2	4
Home-like Environment	11	0	2	0	0	13
Has Been in Hospital for Years	0	0	0	13	0	13
Miscellaneous	8	1	1	15	9	34
Blank	14	0	1	42	4	61
Total	61	2	7	222	26	318

Figure 1



AGE	21 to 30	31 to 40	41 to 50	51 to 60	61 to 70	71 to 80	81 to 99
NUMBER OF RESPONDENTS	3	22	65	85	93	35	5

AGE OF RESPONDENT AND SIZE OF AGE GROUP*

* The age groups of 21-30 and 81+ are not represented on the graph due to the small number of respondents in these two groups (3 and 5 respectively). An additional 14 respondents who did not indicate their age are also not represented on the graph.

Figure Caption

Figure 1. Percent of respondents choosing CSH as the current placement of choice by the respondents age group and size of age group.

References

Meyer, R.J. Attitudes of Parents of Institutionalized Mentally Retarded Individuals Towards Deinstitutionalization. American Journal of Mental Deficiency, 1980, 85, 184-187.

Welsch v. Noot. Consent Decree, No. 4-72 Civil 451, (District of Minnesota, filed September, 1980).